

ECI Library Matters

Down Syndrome Resources (updated)

This issue features library resources on Down syndrome resources. Abstracts of articles on Down syndrome are also included. For a complete listing of library titles, go to the library's online catalog at texashealthlibrary.com.

Library materials may be borrowed upon request. Electronic library resources are available on any device with internet access. Please email any requests or questions to avlibrary@dshs.texas.gov.

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Texas Department of State Health Services

USEFUL INFORMATION

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Services**](#)

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Health monitoring of young children with Down syndrome: A parent-report study. Mengoni, S. E., & Redman, S. (2020). *British Journal of Learning Disabilities*, 48(1), 10-18. <https://doi.org/10.1111/bld.12296>

Accessible Summary: Young children with Down syndrome often have serious Conditions, such as heart or thyroid problems. It is important that health professionals follow guidelines to make sure that these health conditions are diagnosed and treated. We asked parents of children with Down syndrome aged 0–5 years whether their child had received health care as set out in the guidelines. Parents reported that guidelines were mostly followed at birth and for diagnosed health conditions. Guidelines were less likely to be followed after birth and for checking for undiagnosed health conditions.

Background: Children with Down syndrome have an increased risk of serious health conditions, particularly in early childhood. Published guidelines promote the identification and monitoring of health issues and adherence could reduce health inequalities, yet there is limited research about the extent to which health monitoring occurs as recommended. This study aimed to investigate the health monitoring of children with Down syndrome aged 0–5 years in the UK.

Materials and Methods: Twenty-four parents of children with Down syndrome with a mean age of 32 months (10–65 months) participated. They completed a questionnaire about their child's healthcare usage, diagnoses of health conditions and whether health checks had been completed at birth and since birth. The results of the questionnaires were charted and compared to the schedule of checks by the Down Syndrome Medical Interest Group UK.

Results: Children with Down syndrome had high usage of health services and reported significant health issues. There was high adherence to published guidelines for the majority of health checks at birth, although 38% of children had not received all recommended checks. Not all health domains had been monitored since birth for all children, particularly breathing and blood (excluding thyroid). With the potential exception of sleep apnoea, diagnosed conditions appeared to be monitored.

Conclusions: This study suggests that health monitoring after birth and screening for nondiagnosed health conditions is variable for children with Down syndrome. Further research should examine convergence of these findings with medical records and clinicians' experiences across the UK.

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The relationship between chronic health conditions and cognitive deficits in children, adolescents, and young adults with down syndrome: A systematic review. Gandy, K. C., Castillo, H. A., Ouellette, L., Castillo, J., Lupo, P. J., Jacola, L. M., Rabin, K. R., Raghubar, K. P., Gramatges, M. M., & Ginsberg, S. D. (2020). *PLoS ONE*, 15(9). <https://doi.org/10.1371/journal.pone.0239040>

Background: Individuals with Down syndrome are predisposed to a number of chronic health conditions, but the relationship between these conditions and cognitive ability is not clear. The primary objective of this systematic review is to assess this relationship by evaluating studies that measure cognitive performance in the context of Down syndrome-associated chronic health conditions.

Methods: A systematic review was conducted in accordance with the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) guidelines. Studies included in this review (1) included children, adolescent, and young adult participants with Down syndrome and one or more co-occurring health conditions; (2) were quantitative; and (3) reported outcomes related to both chronic health conditions and cognitive performance. A set of predetermined chronic health conditions that are common in Down syndrome (e.g. sleep disorders, congenital heart disease, thyroid disease, seizure disorders, and pulmonary hypertension) were selected based on prevalence rates in Down syndrome.

Results: Fifteen studies met inclusion criteria. The majority these of studies assessed cognitive performance in association with sleep disorders (47%) and congenital heart disease (47%). Fewer studies reported on the effect of thyroid disease (7%) and seizure disorders (7%) on cognitive ability. None of the studies reported cognitive outcomes related to pulmonary hypertension. Of the chronic health conditions evaluated, associations between sleep disorders and cognitive dysfunction were most common among individuals with Down syndrome.

Conclusions: Individuals with Down syndrome exhibit deficits in cognitive ability, particularly related to attention, executive function and verbal processing. These deficits may be further exacerbated by the presence of chronic health conditions, particularly sleep disorders. Individuals with Down syndrome and co-occurring sleep disorders may benefit from early interventions to mitigate their risk for adverse cognitive outcomes.

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How professionals collaborate to support infants and toddlers with disabilities in child care.

Weglarz-Ward, J. M., Santos, R. M., & Hayslip, L. A. (2020). *Early Childhood Education Journal*, 48(5), 643-655.

<https://doi.org/10.1007/s10643-020-01029-5>

As it is common for infants and toddlers with disabilities to receive their early intervention (EI) services in child care programs, this mixed method study examined the experiences of child care and EI providers (e.g., occupational therapists, physical therapists, speech-language pathologists) in collaborating to support infants and toddlers with disabilities in child care settings. Through an online survey and in-person focus groups across a large state, findings indicated that although professionals may interact with each other during EI visits at child care, meaningful collaboration such as including child care providers in Individualized Family Service Plans and embedding intervention strategies into daily routines was minimal. Participants noted many barriers including liability concerns; information sharing; funding and time for collaboration; and minimal training and understanding of child care and EI programming. Participants provided suggestions to support future collaboration including building relationships through shared training, substitute staffing to attend meetings, and clear program and state policies.

IFSP child and family outcomes: Creating clarity with a team-based approach.

DeSpain, S. N., & Hedin, L. (2020). *Young Exceptional Children*.

<https://doi.org/10.1177/1096250620972716>

Mrs. Alvarez, a service coordinator for Child and Family Connections, works with new parents, Mr. and Mrs. Vero to facilitate early intervention services (EIS) for their son. Fernando is a 22-month-old boy with Down syndrome and developmental delays in speech-language, fine and gross motor skills, and cognition. Mrs. Alvarez, an experienced coordinator, knows the importance of family engagement in the Individualized Family Service Plan (IFSP) process and building responsive partnerships. As a result, she dedicates time - beginning with their first meeting - to learning about the family's strengths, needs, and priorities. Mrs. Alvarez and the family notice that Fernando's current IFSP includes present levels of development (PLOD) and associated outcome statements that are vague and outdated. They begin to update and improve Fernando's IFSP and his EIS through a team-based approach.

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Selected Journal Abstracts (continued)

Teachers' perspectives on strength-based and deficit-based instruments for assessing socioemotional development in early childhood.

Sjouml, N., Kiil, A., & Jensen, P. (2021). *Infants & Young Children*, 34(1), 33-45. <https://doi.org/10.1097/IYC.000000000000180>

This study compares teachers' perspectives on three assessment instruments for socio-emotional development in early childhood, which differ in their emphasis on strengths and difficulties in this domain: the Caregiver-Teacher Report Form (C-TRF), the Strengths and Difficulties Questionnaire, Teacher version (SDQ-T), and the Social Emotional Assessment Measure (SEAM).

We examine the teachers' views on the clarity, relevance, and acceptability, as well as estimating average completion times, of the three questionnaires in the context of Danish childcare. Overall, the SEAM was rated better able to convey the child's strengths, was more acceptable by teachers than the C-TRF and SDQ-T, and provided a better basis for talking with parents.

Given its content and acceptability, we conclude this strength-based measure strongly merits inclusion in child assessment of socioemotional development.

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Early interventionists' ratings of family-centered practices in natural environments. p. 266-283. Tomeny, K. R., García-Grau, P., & McWilliam, R. A.

Investigating a "wait and see" mindset among pediatric health care providers: Missed opportunities to refer toddlers with Autism Spectrum Disorder to Part C early intervention. p. 284-305. Edwards, N. M., Kaiser, E., & Stapel-Wax, J. L.

Georgetown University certificate in early intervention: Building provider capacity. p. 306-323. Lane, S. K., Brady, R., & Long, T.

Assessing language delay in twins: Low gesture use and birth history factors. p. 324-336. Foran, L. G., Evans, K. J., & Beverly, B. L.

Practices and reflections of experienced, expert early childhood coaches. p. 337-355. Thompson, P. J., Marvin, C. A., & Knoche, L. L.

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Studies in MTSS problem solving: Improving response to a pre-kindergarten supplemental vocabulary intervention. p. 86-99. Kong, N., Carta, J. J., & Greenwood, C.R.

Primary and secondary effects of Prevent-Teach-Reinforce for young children. p. 100-114. Harvey, H., Dunlap, G., & McKay, K.

An experimental analysis of Prevent-Teach-Reinforce for Families (PTR-F). p. 115-128. Joseph, J. D., Strain, P. S., & Dunlap, G.

The Student Risk Screening Scale for Early Childhood: Additional validation studies. p. 129-146. Lane, K., Buckman, M., Common, E., Oakes, W. P., Lane, N., Schatschneider, C., Perez-Clark Ed S, P., Sherod, R. L., & Menzies, H.

Understanding provider attitudes regarding father involvement in early intervention. p. 147-159. Curtiss, S. L., McBride, B. A., Uchima, K., Laxman, D. J., Santos, R. M., Weglarz-Ward, J., & Kern, J.

Early Intervention and Family-Centeredness in Spain: Description and profile of professional practices. p. 160. García-Grau, P., Martínez-Rico, G., McWilliam, R. A. & Grau, D.

To receive full-text copies of journal articles listed in the Table of Contents, please contact the library staff by email: avlibrary@dshs.texas.gov.

Down Syndrome Resources: New Audiovisual

Down syndrome - second opinion. DVD. 26 min. 2016. (DD0832)

A panel of medical experts discuss how medical life changing decisions have increased the lifespan of patients with Down syndrome. This program features Frankie Antonelli's story, a young athlete born with Down syndrome. Frankie and his mom discuss his achievements in the Special Olympics. The experts explain the health issues, risks, and limitations of children and their families living with Down syndrome.

Down Syndrome Resources: New Book

Bringing your baby with Down syndrome home: A guide to the first month.

Jeannie Visootsak, 2014. (WS 107 V832 2014 ECI)

This book provides a mix of professional advice with the first-hand experience and insight of a parent who was in their shoes just a few years back.

Down Syndrome Resources: Selected Audiovisuals

Being with infants. 108 min. 2018. Streaming.

Daily schedules and caregiving. 92 min. 2016. Streaming.

Down syndrome: The first 18 months, 2nd ed. 108 min. 2010. DVD. (DD0561)

Early intervention for social emotional development. 39 min. 2017. DVD. (DD0827)

Infant toddler learning environment. 43 min. 2017. DVD. (DD0825)

Down Syndrome Resources: Selected Books

Addressing challenging behaviors and mental health issues in early childhood. Mojdeh Bayat. 2020. (LB 1139.25 B356 2020 ECI)

Caring for our children: National health and safety performance standard guidelines for early care and education programs, 4th ed. 2019. (LB 1139.23 C277 2019)

Does time heal all? Exploring mental health in the first 3 years. Miri Keren, 2018. (WS 350 K39 2018 ECI)

The developmental systems approach to early intervention. Michael J. Guralnick, 2019. (LC 4019.3 G978e 2019 ECI)

Finding your way with your baby: The emotional life of parents and babies. Dilys Daws, 2015. (WS 105.5 E5 D272 2015 ECI).

Fine motor skills in children with Down syndrome: A guide for parents and professionals, 3rd ed. Maryanne Bruni, 2016. (WS 107 B896f 2015 ECI).

Down Syndrome Resources: Selected Books (continued)

Off to a good start: A behaviorally based model for teaching children with Down syndrome. Book 1, Foundations for learning. Emily A. Jones, 2019. (WS 107.1 J76 2019 ECI)

The parent's guide to Down syndrome. Jen Jacob, 2016. (WS 107 J15p 2016 ECI)

Practical solutions to practically every problem: The survival guide for early childhood professionals. Steffen Saifer, 2017. (LB 1140.2 ST817 2017)

Prevent-Teach-Reinforce for families: A model of individualized positive behavior support for home and community. Glen Dunlap, 2017. (LB 1139 P944 2017 ECI).

Twelve essential topics in early childhood: A year of professional development in staff meetings. Nancy P. Alexander, 2018. (LB 1775.6 AL374 2018).

Down Syndrome Resources: Selected Websites

Local Down Syndrome Associations: Texas has sixteen local Down syndrome associations. Please visit individual association websites for more information.

- **BUDS - Better Understanding of Down Syndrome:** budslubbock.org
- **Down By the Border:** downbytheborder.org
- **Down Syndrome Association of Brazos Valley:** dsabv.org
- **Down Syndrome Association of Central Texas:** dsact.org
- **Down Syndrome Association of El Paso:** dsaep.org
- **Down Syndrome Association of Houston:** dsah.org
- **Down Syndrome Association of South Texas:** dsastx.org
- **Down Syndrome Guild of Dallas:** downsyndromedallas.org
- **Down Syndrome Partnership of North Texas:** dspnt.org
- **East Texas Down Syndrome Group:** etdsg.org
- **Galveston-Houston Families Exploring Down Syndrome:** ghfeds.org
- **Heart of Texas Down Syndrome Network:** hotdsn.org
- **Panhandle Down Syndrome Guild:** pdsq.org
- **Red River Valley Down Syndrome Society:** parisreach.org
- **Rio Grande Valley Down Syndrome Association:** rgvdsa.org

Down Syndrome Resources: Selected Websites (continued)

MedlinePlus, an online medical resource provided by the National Library of Medicine, offers resources about Down syndrome. For more information, go to medlineplus.gov/downsyndrome.html.

National Down Syndrome Society mission is to be the national advocate for the value, acceptance and inclusion of people with Down syndrome. This website is immense and attempts to be the comprehensive information source on Down syndrome. For more information, go to ndss.org.

National Institutes of Health provides DS-Connect®, a powerful resource where people with Down syndrome and their families can connect with researchers and health care providers, express interest in participating in certain clinical studies on Down syndrome, including studies of new medications and other treatments, and take confidential health-related surveys aimed at better understanding of the health of people with Down Syndrome across their lifespans. For more information, go to dsconnect.nih.gov/

National Human Genome Research Institute provides an online resource on Down syndrome. For more information, go to genome.gov/Genetic-Disorders/Down-Syndrome.

Texas Department of State Health Services Down Syndrome provides online resources for new and expecting parents. For more information, go to dshs.texas.gov/birthdefects/downsyndrome/.